



## Steps towards equitable vaccination: A rapid review of factors to support vaccine uptake in children and youth with medical vulnerability

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### Land Acknowledgments

Solutions for Kids in Pain's Administrative Centre is located in Mi'kma'ki, the ancestral and unceded territory of the Mi'kmaq People. We acknowledge them as the past, present, and future caretakers of this land. We are all Treaty people.

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### About Solutions for Kids in Pain

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### General Disclaimer

This document was developed by Solutions for Kids in Pain (SKIP) and was guided by the best available peer-reviewed scientific evidence at the time of publication. This report may not fully reflect all the scientific evidence available at the time it was prepared as other relevant scientific findings may have been reported since.





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### **Abbreviations**

COVID-19 Coronavirus Disease 2019 HPV Human Papillomavirus

ICC Immunizing Children with Confidence

SAGE Strategic Advisory Group of Experts on Immunization Working

Group

SKIP Solutions for Kids in Pain USA United States of America WHO World Health Organization

### **Key Definitions**

**Medical Vulnerability:** There is not one existing definition of medical vulnerability. Expert consultation and a literature review adapted the following definition from Woodruff et al., who examined risk factors for COVID-19 in children: Medical Vulnerability is defined as one or more of the following: pulmonary or airway disorders, neurological disorders, cardiac disorders, diabetes, prematurity (up to and including the age of two), feeding tube dependence, or immunodeficiency resulting from other chronic conditions (such as gastrointestinal or liver disease, chronic metabolic disease, blood disorders or renal disease, cancer).<sup>1</sup>

**Childhood vaccines:** In this review, we use the term childhood vaccines to refer to a group of approved vaccinations administered during childhood. Unless otherwise specified, this term indicates that a group of vaccinations was studied.





### Summary

Overview: Healthcare professionals and families face unique challenges when deciding on vaccinations for children and youth with medical vulnerability. This rapid review aimed to identify factors contributing to vaccine hesitancy and vaccine confidence promotion practices and policies focused on medically vulnerable children and youth.

Methods: A comprehensive search for published literature was conducted in three databases to identify articles that addressed factors impacting vaccine uptake and confidence specific to children and youth with medical vulnerability. Studies were included if they had data on vaccine confidence or uptake in children up to 18 years of age, meeting our definition of medical vulnerability. Then, guided by the Strategic Advisory Group of Experts on Immunization (SAGE)'s vaccine hesitancy matrix, we conducted a narrative review around three categories: 1) contextual influences, 2) individual and group influences and 3) specific issues of vaccine/vaccination.

Results: A total of 28 studies were included. Our findings show that factors within all three categories of the vaccine hesitancy matrix play a role in vaccine hesitancy in children and youth with medical vulnerability. Families of children and youth with medical vulnerability were concerned about the interaction of the vaccine with their child's underlying medical condition. They wanted more information about the specific risks and benefits to their child. When trusted healthcare professionals discussed vaccine safety and recommendations with families of children and youth with medical vulnerability, vaccine uptake was greater. Knowledge of vaccine-preventable disease and misconceptions about side effects also impacted vaccine uptake.

Implications and next steps: Further research and knowledge mobilization are needed to address the specific information need of families and healthcare professionals who care for children and youth with medical vulnerability. Trusted relationships between families and healthcare professionals must be the center of vaccination programs, along with opportunities to provide vaccines in settings where children and youth with medical vulnerability are already receiving care.







### Background

The World Health Organization (WHO) has declared vaccine hesitancy among the top ten global threats.<sup>2</sup> Vaccines are considered one of the most successful public health interventions, and countries with effective vaccination programs have reduced or eradicated many vaccine-preventable diseases.<sup>3</sup> Despite this, vaccination rates for COVID-19 and routine childhood immunization are below what they should be, and vaccine hesitancy rates have increased. Furthermore, research indicates that since COVID-19, there has been a decrease in routine childhood immunizations.<sup>4</sup> This disruption could have a significant global impact, especially for those with a high risk of complications related to COVID-19 or vaccine-preventable diseases.

### **Children and Youth with Medical Vulnerability**

Among the most vulnerable to COVID-19 and vaccine-preventable diseases are children, youth, and/or families susceptible to infection and severe outcomes due to complex medical conditions. Children and youth with medical vulnerability face increased medical risk due to infection and are disproportionately impacted by disruptions to health, social, community, and education services during the COVID-19 pandemic.<sup>5</sup> For example, many families of children and youth with medical vulnerability faced disruptions in community support services such as home care.<sup>6</sup> Learning was disrupted by school closures or by moving to virtual classrooms. Many children and youth with medical vulnerability miss out on crucial therapy. respite, and socialization inside schools.<sup>7</sup>

### Medical vulnerability refers to:

- Pulmonary or airway disorders
- Neurological disorders
- Cardiac disorders
- Diabetes
- Prematurity
- Feeding tube dependence
- Immunodeficiency resulting from other chronic medical conditions or cancer

It is vital to recognize that the COVID-19 pandemic exacerbated pre-existing inequities and isolation for families with children and youth with medical vulnerability. A report by the National Children Bureau in Northern Ireland outlined the impacts that COVID-19 had on children and youth with special education needs and disabilities. It highlighted that these challenges are not new; they were exacerbated during the pandemic. As one parent described, "I think maybe COVID should waken up a lot of people and saying, we don't have enough support for children with special needs. We just don't have it and how are we going to get it? But then is that up to parents to keep going and going and going? [It's] very hard to keep fighting all the time..." (pg 64).8 The pandemic has further highlighted the social and healthcare inequities faced by children and families in equity-seeking groups. <sup>5,6,9,10</sup> This is the case for increased risk related to health outcomes and extends to vaccination services and programs.





### **Defining Vaccine Hesitancy**

Understanding the need to address vaccination rates and the complexity of vaccine hesitancy, the Strategic Advisory Group of Experts on Immunization (SAGE) was established to advise the WHO. SAGE (2015) defined vaccine hesitancy as the "delay in acceptance or refusal of vaccination despite the availability of vaccination services. Vaccine hesitancy is complex and context-specific, varying across time, place, and vaccines. While high levels of hesitancy lead can lead to low vaccine uptake, low levels of hesitancy do not necessarily mean high vaccine uptake or demand. Vaccine hesitancy is influenced by factors such as complacency, convenience, and confidence". The Vaccine Hesitancy Determinants Matrix from the SAGE working group displays these factors affecting the behavioral decision to accept, delay or reject some or all vaccines under three categories: contextual, individual and group, and vaccine/vaccination-specific influences. The matrix helps identify critical indicators that help tailor vaccine hesitancy policies and programs to support vaccine uptake in specific populations.

### **Vaccine Hesitancy in High-Risk Populations**

The COVID-19 pandemic and vaccination rollout have highlighted the need to examine vaccine hesitancy and parent and caregiver decision-making around vaccine acceptance and uptake. Research on vaccine hesitancy related to childhood vaccines is often conducted in the general pediatric population. This approach risks missing the complexity of the social and structural process, historical experiences, and ongoing marginalization that may contribute to vaccine uptake.<sup>9,12</sup> This approach may not be able to address the unique needs of equity-seeking groups.<sup>9</sup>

The specific constructs that impact vaccine hesitancy in parents and caregivers of children and youth with medical vulnerability must be considered. While factors contributing to COVID-19 vaccine hesitancy in children with medical vulnerabilities overlap with the general pediatric population, there are also distinct differences. <sup>13</sup> Fear of exacerbating underlying conditions and concern that COVID-19 vaccine safety data does not cover their child's specific medical needs were unique factors for families of medically vulnerable children. This rapid review examines the literature for factors that impact vaccination uptake for children and youth with medical vulnerability and the interventions that health professionals and health systems can use to support these families with decision-making around vaccinations.





### **Objectives**

This rapid review was completed as part of the Immunizing Children with Confidence project. Led by Children's Healthcare Canada and SKIP, the objectives of this review were to identify effective vaccine hesitancy prevention or vaccine confidence promotion practices and policies focused on medically vulnerable children and youth.

This rapid review aims to build Canadian health professionals' capacity and confidence as vaccinators and vaccine promoters serving children and youth through tailored interventions and resources. More specifically, this project will improve access to, awareness, and use of knowledge and resources available to healthcare professionals and decision makers responsible for vaccine communication and vaccine provision with children, youth, and families. The resources, co-developed with health professionals, and family partners, will enable health professionals to promote vaccination safely and confidently, including those at increased risk due to COVID and other vaccine-preventable infectious diseases (e.g. children with disabilities, medical complexity, acute illness).

### **Rapid Review Questions:**

- » What factors affect vaccine uptake in children and youth with medical vulnerability?
- » What interventions exist for health professionals to increase the uptake of vaccinations in children and youth with medical vulnerability?

### Methods

### Partner engagement

This rapid review was completed in collaboration with the <u>Immunizing Children with Confidence Advisory Committee</u>, comprised of researchers, health professionals, family partners, and decision makers across Canada. They provided input on developing the research questions, literature search, analysis of findings, writing of results, and dissemination of the final report.

### **Search strategy**

This rapid review was conducted using the Cochrane Rapid Review Methods Group methods.<sup>14</sup> The search strategy was developed in collaboration with a medical librarian. Database searches were conducted in MEDLINE, CINAHL, and Embase from database inception to April-May 2022. A sample search strategy is available in Appendix 1.





### **Eligibility criteria**

English language peer-reviewed scientific articles were identified for inclusion if they 1) discussed children and youth aged <18 years with one or more medical vulnerabilities (see definition on page 4); 2) reported on any childhood vaccination; 3) focused on factors related to vaccine uptake, vaccine confidence, and/or barriers to vaccination. Studies were excluded if they did not 1) primarily focus on children and youth with medical vulnerability or 2) discuss modifiable factors related to vaccine uptake or confidence.

### Screening and selection

Covidence<sup>15</sup> was used for abstract and full-text screening. One reviewer screened all abstracts for eligibility. A second reviewer screened 20% of all search results. Disagreements were resolved through consultation or the involvement of a senior reviewer as needed. One reviewer screened all full-text articles for eligibility. A senior reviewer was consulted by the first reviewer as required.

### **Data extraction and synthesis**

One reviewer extracted data with regular meetings with a senior reviewer to ensure rigour and consistency and address any uncertainties. Extracted data included author, publication year, country, study design, study setting, vaccination studied, age group, primary medical condition, vaccination rates, key concepts, and recommendations.

Using the WHO's Vaccine Hesitancy Determinants Matrix<sup>11</sup>, key outcomes were grouped into the following categories: 1) contextual influences, 2) individual and group influences, and 3) vaccine/vaccination-specific issues. Two reviewers coded the critical outcomes of each study using the vaccine hesitancy matrix categories and subcategories. Any discrepancies were discussed with a senior reviewer. Finally, results are synthesized using a narrative approach.





### Results

### **Literature Search**

Database searches identified 6292 records. After duplicates were removed, 4641 unique abstracts remained for review. Of these, 3983 studies were ineligible. A total of 658 full texts were reviewed, of which 630 studies were excluded. Twenty-eight full texts met the inclusion criteria. Refer to Figure 2 for the PRISMA review flowchart, including reasons for exclusion.

### **Characteristics of included studies and populations**

Of the 28 articles meeting inclusion criteria, there was one systematic review, 22 cross-sectional studies, one qualitative study, two retrospective chart review studies, and two prospective studies. Analyses were conducted in Canada, the United States, Turkey, France, Saudi Arabia, India, Australia, the People's Republic of China, and the Republic of Korea. Refer to Table 1 for full study details. Studies most frequently examined the influenza vaccine (n=14), childhood vaccines (n=9), COVID-19 vaccines (n=4), and HPV vaccines (n=1).

### Types of medical vulnerability reported: (n=28)

- Multiple comorbidities (e.g. sickle cell disease, diabetes, cardiac disease) (n=6)
- Cancer (n=5)
- Chronic medical conditions resulting in hospital admission (n=4)
- Gastrointestinal disorders (n=4)
- Disorders of the kidney (n=3)
- Neurological disorders (including autism, down syndrome, intellectual disability) (n=3)
- Pulmonary or airway disorders (n=2)
- Rheumatoid disease (n=1)





Table 1: Characteristics of Included Studies

Author, Year, Country	Study design	Vaccine type	Pediatric medical vulnerability population	Study aim(s)
Akgun, 2021, Turkey <sup>16</sup>	Cross-sectional	COVID- 19	Pediatric rheumatic disease	To investigate concerns and acceptability regarding the COVID-19 vaccine of parents of pedRD and features of vaccine acceptance, hesitancy, and refuse status.
Norman, 2021, USA <sup>17</sup>	Systematic review	Influenza	Multiple comorbidities *conditions not specified	A systematic review of published interventions of influenza vaccine coverage in children with medical comorbidities.
Wimberly, 2021, USA <sup>18</sup>	Cross-sectional	COVID- 19	Pediatric Cancer	To determine the willingness/hesitancy of caregivers to vaccinate themselves and their children who had cancer.
Longuet, 2014, France <sup>19</sup>	Prospective	Childhood vaccines	Inflammatory Bowel Disease	To compare immunization status to the general pediatric population and results of previous studies in IBD groups and look for causes leading to potential delay.
AlGoraini, 2020, Saudi Arabia <sup>20</sup>	Cross-sectional	Childhood vaccines	Hospital admission *conditions not specified	To assess the magnitude of parents' hesitancy toward vaccines and to determine the reason for parents of partially vaccinated and unvaccinated children.
Albaugh, 2021, India <sup>21</sup>	Cross-sectional	Childhood vaccines	Hospital admission *conditions not specified	To document the vaccination status of hospitalized children and assess vaccination barriers perceived by caregivers and health professionals.
Cherven, 2019, USA <sup>22</sup>	Cross-sectional	HPV	Pediatric cancer	To determine the relationship between HPV vaccine intent and subsequent vaccination among cancer survivors.
Cameron, 2016, USA <sup>23</sup>	Retrospective chart review	Influenza	Asthma or pulmonary disease	To examine reasons for refusal among pediatric patients admitted during influenza season.
Langkamp, 2020, USA <sup>24</sup>	Cross-sectional	Childhood vaccines	Down syndrome	To determine the prevalence of vaccine hesitancy and refusal among parents of children with Down syndrome at 19 months of age.
Huth, 2015, Canada <sup>25</sup>	Prospective	Influenza	Crohn's disease, Ulcerative colitis IBD- unclassified	To determine whether educational and vaccine accessibility interventions improved vaccination rates and determine factors associated with obtaining vaccination.





Author, Year, Country	Study design	Vaccine type	Pediatric medical vulnerability population	Study aim(s)
Holland, 2020, USA <sup>26</sup>	Cross-sectional	Childhood vaccine	Crohn's disease w/ IBD Non IBD Group (abdominal pain, acid reflux, constipation)	To compare current vaccination rates and parental beliefs toward vaccine safety in patients with and without IBD in a tertiary care children's hospital.
Choi, 2020, US <sup>27</sup>	Retrospective chart review	Childhood vaccines	Pediatric cancer	To evaluate vaccination rates and knowledge of recommended vaccination practices in childhood cancer survivors.
Doganis, 2012, Greece <sup>28</sup>	Cross-sectional	Influenza	Pediatric cancer	Describe the factors that may have contributed to the high compliance rate to vaccination programs in the pediatric oncology department.
Kaya, 2017, Turkey <sup>29</sup>	Cross-sectional	Influenza	Asthma	To determine the knowledge, beliefs, and attitudes of patients with allergic rhinitis and asthma and their parents related to influenza vaccination.
Blyth, 2016, Australia <sup>30</sup>	Cross-sectional	Influenza	Medical comorbidities *condition(s) not specified	To determine the effectiveness of TIV in children with risk factors for severe disease and to compare vaccine uptake, parental attitudes, and prescriber recommendations in children with and without risk factors for severe disease.
Chau, 2017, China <sup>31</sup>	Cross-sectional	Influenza	Medical comorbidities *condition(s) not specified	To identify factors determining influenza vaccination uptake among children with a chronic condition.
Choi, 2021, Korea <sup>32</sup>	Cross-sectional	COVID- 19	Medical comorbidities *condition(s) not specified	To investigate parental and child acceptability of COVID-19 vaccination, and the factors affecting their acceptability
Hofsetter, 2021, USA <sup>33</sup>	Cross-sectional	Influenza	Hospital admission *conditions not specified	To examine influenza-related knowledge, beliefs, and experiences of caregivers with hospitalized children and assess their association with decision-making about influenza vaccination before and during hospitalization.
Peleg, 2015, USA <sup>34</sup>	Cross-sectional	Influenza	Gastrointestinal diseases	To determine vaccination rates and to identify the main reasons for non-vaccination in children.





Author, Year, Country	Study design	Vaccine type	Pediatric medical vulnerability population	Study aim(s)
Rao, 2018, USA <sup>35</sup>	Cross-sectional	Influenza	Hospital admission *conditions not specified	To determine health professional and parental attitudes toward inpatient influenza vaccination and explore potential barriers to inpatient influenza vaccination.
Rathore, 2008, USA <sup>36</sup>	Cross-sectional	Influenza	Sickle cell disease; congenital heart disease; HIV; diabetes	To determine caregiver knowledge and perceptions regarding the influenza vaccine and assess other barriers, such as availability and perceived safety of the vaccine.
Sahni, 2020, USA <sup>37</sup>	Cross-sectional	Childhood vaccines	Autism, non-ASD developmental disorder, rheumatologic conditions, children receiving care	To examine vaccine hesitancy and beliefs about causes of a child's ASD diagnosis among parents, parents of children with other chronic conditions, and parents of children from the general pediatric population.
Sampson, 2011, Scotland <sup>38</sup>	Qualitative interviews	Influenza	Respiratory, heart, renal, liver, and neurological diseases, diabetes, immunosuppression	To explore parental reasons for non-uptake of influenza vaccination in young at-risk groups.
Scheuerman, 2017, Isreal <sup>39</sup>	Cross-sectional	Influenza	Kidney disease	To evaluate the annual influenza vaccination rate in pediatric patients with renal diseases and verify the main reasons for non-vaccination in this patient group.
Skeens, 2022, USA <sup>40</sup>	Cross-sectional	COVID- 19	Pediatric cancer	To describe vaccine hesitancy in parents of children with cancer for their child and self and examine the impact on the association between COVID exposure and hesitancy.
Tran, 2020, USA <sup>41</sup>	Cross-sectional	Childhood vaccines	Nephrotic syndrome	To evaluate immunization practices by assessing parental knowledge and understanding of immunizations.
Tuckerman, 2018, Australia <sup>42</sup>	Cross-sectional	Influenza	Special medical risk conditions *conditions not specified	To determine levels of influenza vaccination uptake in children with SMRC, and explore characteristics associated with receipt of the influenza vaccine.
Yen, 2021, Taiwan <sup>43</sup>	Cross-sectional	Influenza	Intellectual disability	To describe the profile of seasonal influenza vaccination uptake and to examine its determinants for children and adolescents with ID living in the community.





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### **Vaccination Factors**

The decision to accept, delay or reject a vaccine depends on several factors that can either be enabling or act as a barrier. The SAGE Vaccine Hesitancy Matrix maps the key factors influencing vaccination decisions into three categories: 1) contextual, 2) individual and group, and 3) vaccine/vaccination-specific issues. Key findings from included studies were coded into each category and subcategory.

Figure 1. Vaccine Hesitancy Matrix<sup>11</sup>

### Contextual influences

### Influences arising due to historic, socio-cultural, environmental, health, system/institutional, economic or political factors

- a. Communication and media environment
- b. Influential leaders, program gatekeepers, anti- or pro-vaccination lobbies
- c. Historical influences
- d. Religion/culture/gender/socio-economic
- e. Politics/policies
- f. Geographic barriers
- g. Perception of the pharmaceutical industry

### Individual and group influences

### Influences arising from personal perception of the vaccine or influences of the social/peer environment

- a. Personal, family and/or community members' experience with vaccination, including pain
- b. Beliefs, attitudes about health and prevention
- c. Knowledge/awareness
- d. Health system and providers trust and personal experience
- e. Risk/benefit (perceived, heuristic)
- f. Immunization as a social norm vs. not needed/harmful

### Vaccine/ vaccination specific factors

### Directly related to vaccine or vaccination

- a. Risk/benefit (epidemiological and scientific evidence)
- b. Introduction of a new vaccine or a new recommendation for an existing vaccine
- c. Mode of administration
- d. Design of vaccination programme (e.g., routine or mass vaccination campaign)
- e. Reliability and/or source of supply of vaccine and/or vaccination equipment
- f. Vaccination schedule
- g. Costs
- h. Strength of the recommendation and/or knowledge base and/or attitude of healthcare professionals





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### **Synthesis of Results**

### Category 1: Contextual influences

Geographical barriers were the most reported contextual factor, with 21% of studies reporting barriers to accessing the vaccine impacted vaccination uptake (n=6). Communication and media factors were found in 7% of articles (n=2), along with religion/culture/socio-demographic factors (n=2).

Reported geographical barriers included distance and time to the vaccination clinic. For example, in one study, vaccination rates were higher when the vaccine was offered at the hospital where children were already receiving specialist care versus when it was provided in the community.<sup>25</sup> Another study reported that while accessibility was not a significant factor, caregivers would have been more likely to vaccinate their children if it had been offered at the specialty clinic where their child attended regular appointments.39

Not all studies reported geographical barriers to obtaining vaccinations. For example, one study which examined influenza vaccination rates in children admitted to the hospital said that 72% of parents did not find distance and time to the clinic as a barrier.42

Communication and media factors were raised in a limited number of articles. One article examining influenza vaccinations in children and

### **Top Contextual Influences** (n=28 of studies mentioning)

- Geographical barriers (n=6)
- Communication and media environment (n=2)
- Politics/Policies (n=1)
- · Religion/culture/gender/socioeconomic (n=1)

Factors not mentioned:

Historical influences Influential leaders, immunization program gatekeepers, anti/pro-vaccination lobbies Perception of the pharmaceutical industry

youth with cancer reported that mass media presented confusing and controversial information about vaccination safety and effectiveness.<sup>28</sup> However, another study said the media could positively promote correct information about vaccinations and increase public awareness.<sup>20</sup>

### Category 2: Individual and group influences

Individual and group influences accounted for the most significant category of factors associated with vaccination decisions and included personal beliefs, perceptions, and social contributions. Specifically, 54% of studies reported that risk/benefits (e.g. an idea that there is no need to vaccinate or low perceived risk of a vaccine-preventable





disease) played a role in vaccine hesitancy (n=15). In addition, 36% of studies identified knowledge/awareness as a factor (e.g. parental misconceptions about vaccines or insufficient understanding of the vaccine-preventable disease) (n=10), and 32% of studies identified beliefs and attitudes (e.g. personal philosophical reasons) played a role (n=9).

Several studies reported a high frequency of perceived risks or benefits of the need to vaccinate their child against a particular vaccine-preventable disease. For example, parental perception of the severity of HPV increased the odds of vaccine intent.<sup>22</sup> Likewise, a study looking at influenza vaccination rates in children with chronic conditions reported that parents who believed their child was at high risk of acquiring influenza had high vaccination uptake.<sup>31</sup> Scheuerman et al. (2017) also demonstrated that parental belief that the vaccine might cause influenza resulted in 70% of parents choosing not to vaccinate their children.<sup>39</sup>

Knowledge and awareness factors can beneficially impact vaccination uptake. For example, one systematic review showed that education directed at parents increased influenza vaccination uptake by 60% in children

### Top Individual and Group Influences

(n=28 of studies mentioning)

- Risk/benefits (perceived) (n=15)
- Knowledge/awareness (n=10)
- Beliefs, attitudes(n=9)
- Health system and providers' trust and personal experience (n=5)
- Personal, family, community member experience with vaccination, including pain (n=4)
- Immunization as a social norm (n=1)

and youth with comorbidities.<sup>17</sup> Similarly, parental knowledge about influenza vaccines and influenza as illness significantly impacted vaccination uptake in hospitalized children.<sup>33</sup> Importantly, lack of knowledge can also be a barrier. A study of influenza vaccine in children and youth with medical vulnerability reported only 54.3% of parents being aware of the recommendation for the vaccination and 59.3% of parents unaware that the immunization was free.<sup>42</sup>

### Category 3: Vaccine-vaccination specific issues

Half of the studies reported that recommendations from a health professional to obtain the vaccine were a vital contributor to vaccination rates (n=14). In addition, scientific evidence of risk/benefits (e.g. the fear of getting sick after a vaccination despite evidence of safety) was identified in 39% of studies (n=11), and the design of vaccination program in 11% of studies (n=3).

Decisions around vaccine uptake are commonly influenced by the strength of a health professional's recommendation. Most parents (91%) of children and youth with Irritable





Bowel Disease reported that they would accept the vaccine if their child's specialist recommended it and had strong scientific evidence.<sup>25</sup> Likewise, parents of hospitalized children and youth and parents of children with gastrointestinal disorders were more likely to vaccinate their child against influenza if recommended by a health professional.<sup>33,34</sup> In one case, parents felt that a recommendation from the primary care provider was beneficial.<sup>33</sup> Parents of children who had survived cancer were more likely to obtain the HPV vaccine for their child if recommended by their child's oncologist.<sup>22</sup>

Not surprisingly, a lack of health professional recommendations can be a vaccine barrier. For example, parents of children and youth with Irritable Bowel Disease reported that their child's gastroenterologist should also discuss vaccination recommendations in addition to a recommendation from their primary care provider.<sup>26</sup> Moreover, only 48% of families reported that their primary care provider recommended vaccinations following a cancer diagnosis.<sup>27</sup> The absence of a physician's recommendation was associated with a significantly higher rate of non-vaccination of influenza in children with chronic medical conditions compared to those who received a recommendation.36

Another common factor was understanding the scientific evidence of the risks and benefits of vaccinations specific to their child's medical condition. The perception of the risk of the vaccine was a barrier to children with medical vulnerability obtaining their vaccinations. For example, parents of children being treated for

### Top Vaccine/Vaccination Specific Issues

(n=28 of studies mentioning)

- Strength of recommendations (n=14)
- Risk/benefits of vaccine/vaccination (n=11)
- Design of vaccination program (n=3)
- Reliability and/or source of vaccine (n=2)
- Mode of vaccine administration (n=1)
- Vaccination Schedule (n=1)
- Costs (n=1)

Issues not mentioned:

Introduction of a new vaccine

cancer reported concerns about scientists' differing opinions around the safety and effectiveness of the influenza vaccination.<sup>28</sup> Multiple studies across various causes of medical vulnerability and vaccine types reported that a fear of side effects and of causing further medical complications resulted in decreased vaccine uptake.<sup>19,20,23,24,28,29,39</sup> However, some studies showed that the perceived benefit of vaccines outweighed the perceived risk of the vaccine. For example, in children with a reported intellectual disability, a more moderate to severe (compared to mild) disability level was correlated with high influenza rates.<sup>44</sup>

Finally, the design of the vaccination program can impact vaccination uptake. For this review, we included factors such as the availability of up-to-date vaccination records and vaccination reminders in this subcategory. In a systematic review on improving





influenza vaccination in children with comorbidities, Norman et al. (2021) reported that clinic process changes and vaccination reminders to parents and healthcare professionals positively impacted vaccine uptake.<sup>17</sup> For example, inter-clinic collaboration, access to vaccine records in clinics, and sharing resources influenced whether a child received their influenza vaccine. When considering vaccination opportunities for children and youth admitted to the hospital, the non-availability of vaccinators for admitted patients resulted in missed vaccination opportunities.<sup>21</sup>

### **Socio-demographic Factors**

Socio-demographic factors impact vaccine hesitancy. <sup>11</sup> While this review focused on vaccine uptake in children and youth with medical vulnerability, we must recognize the role of intersectionality and other factors that might influence vaccine uptake for families. For example, experiences of harm or discrimination within the healthcare system contribute to lower vaccine uptake, particularly in cases of equity-seeking groups.

Unfortunately, many included studies did not examine or report socio-demographic findings. The results were mixed for the studies that provided conclusions based on socio-demographics. Several studies reported no differences based on gender, education, and income level. <sup>16,24,27</sup> A study that looked at missed opportunities for the influenza vaccine in children with respiratory disease reported that parents who were White were more likely to decline the influenza vaccination in hospitals compared to parents who were Black or classified by the author as another race.<sup>23</sup> In this hospitalbased study in the United States, parents who were White had high rates of private insurance as compared with parents who were Black (70% vs. 42%), and White parents indicated a preference to receive their vaccinations outside of the hospital, at their primary care clinic. Two studies also reported findings related to child sex. A survey of influenza vaccination in children and youth with kidney disease found that male children had higher vaccination rates.<sup>39</sup> The authors explain that these differences may be influenced by family ethnicity; however, the article does not consider race or ethnicity in the demographic analysis. Another study found no significant difference in vaccination rates for males and females.<sup>23</sup> Caution should be made in interpruting these findings, given that socio-demographic factors were not a primary objective/aim of any of these studies.

Finally, the vaccine hesitancy matrix provides a broad, multilevel framework examining the factors associated with vaccine uptake. However, there are some concerns with its ability to represent structural factors such as equitable access to vaccine availability and accessibility of vaccination programs. 12,45 It is critical to consider and address societal and institutional barriers that equity-seeking groups face.





### Implications for Research, Practice, and Policy

### **Overview**

The second object of this rapid review was to understand potential interventions which can support children and youth with medical vulnerability, families, and healthcare teams to make informed vaccination decisions. Implications for practice and policy were extracted from all included studies (n=28).

Table 2. Research, policy, and clinical implications.

### Theme 1: More extensive studies that look at the specific needs of parents/caregivers and children and youth with medical vulnerability

- ⇒ Evaluate interventions that improve vaccine coverage, comparing intervention types to reduce the risk of vaccine-preventable disease in children and youth with medical comorbidities.<sup>17</sup>
- → Understand family and provider perspectives on providing vaccinations in settings where children and youth are already receiving care.<sup>36</sup>
- Test new strategies to educate parents and youth on the importance of vaccinations and explore programs that meet families where they are.<sup>37</sup>

### Theme 2: Increase knowledge of vaccination safety and effectiveness in children and youth with medical vulnerability

- ⇒ Develop resources for health professionals and families that support vaccination conversations, including information for families that address concerns around vaccine safety and fear of making their child's medical symptoms worse.<sup>26</sup>
- ⇒ Further studies specifically explore the barriers children and youth with medical vulnerability face when seeking information and making decisions about vaccinations.<sup>34</sup>

### Theme 3: Develop specific vaccination guidelines for children and youth with medical vulnerability

- → Consolidate existing guidelines for children with medical vulnerability into a health professional-friendly resource.<sup>28</sup>
- → Health professionals may not recommend a vaccination due to perceived contradiction with a child's medical condition. Develop best practice evidence summaries for health professionals explaining potential vaccination contradictions for complex medical conditions.<sup>21</sup>

# Research and Knowledge Mobilization Implications





### **Policy Implications**

Clinical Implications

### Theme 1: Improve immunization registries and reminder systems

- ⇒ Expand or establish immunization registries to remove the burden from families and increase accuracy in recalling vaccination history.<sup>20</sup>
- ⇒ Parents often report their children being up to date on vaccinations when they miss them. Families had difficulty recalling vaccine status, particularly for vaccines that were not mandated for school attendance.<sup>26</sup>

### Theme 2: Policies to promote vaccination opportunities during existing healthcare encounters

Healthcare institutions should implement policies and practices that support the delivery of vaccinations to children, youth, and their families where and when they are already receiving care. Families of children and youth with medical vulnerability under-vaccinated had recent contact with healthcare facilities. Screening for vaccination and removing logistical barriers to vaccine access within healthcare facilities can improve vaccination inequalities.<sup>21</sup>

### Theme 1: Ensure that care teams are coordinated in their communication around vaccination recommendations and the logistics of vaccine delivery

- ⇒ Specialists are uniquely positioned to improve vaccination rates in medically vulnerable populations. Families want both their specialists and primary care providers to address vaccination needs.<sup>20</sup>
- ⇒ Parents identified that specialist health professionals played an essential role in their intent to vaccinate, yet reported a low percentage of receiving vaccination recommendations from their specialist teams.<sup>22</sup>
- → More coordination is needed between specialty and primary care physicians to offer a consistent message, inform, educate parents and address any misconceptions regarding the influenza vaccine.<sup>37</sup>

### Theme 2: Provide educational opportunities to support health professionals with the benefits of vaccination in medically vulnerable populations

- Provide valuable opportunities and resources for physicians to quickly obtain information about vaccination best practices in children and youth with medical vulnerability.<sup>26</sup>
- → Provide targeted training to help health professionals evaluate parental concerns about vaccinations and provide resources to increase parental knowledge and attitudes towards vaccination.<sup>20,22,27,33,35</sup>





### **Needle Pain and Fear**

Pain and discomfort related to vaccines and/or fear of needles commonly contribute to vaccine hesitancy. 46,47 Fear of pain and discomfort related to needles can lead to delays or avoidance of vaccinations and can also result in avoidance of other healthcare interactions. The impact of unmanaged needle pain and fear can extend beyond one single procedure. 48

Our review found that one study reported pain or fear is associated with low vaccine uptake.<sup>23</sup> This is not surprising as, historically, pain concerns related to vaccinations are often not probed.<sup>49</sup> To the best of our knowledge, there is a gap in the literature regarding the role that needle pain and fear play in vaccination uptake in children and youth with medical vulnerability.

Fortunately, there are practical, evidence-informed strategies to improve vaccine experiences and reduce needle fear and pain associated with vaccines. <sup>50–52</sup> SKIP has developed resources for healthcare professionals and families to help prevent and manage pain and needle fears. See Appendix 3 for more needle fear and pain resources.

### **Needle Pain and Fear Facts**

Vaccinations are the most common painful needle procedures.

### 2 out of 3

children have some degree of needle fear.

### 20-50%

of adolescents are fearful of needles.

### 7% of parents and 8% of children

report that a fear of needles is the primary reason for avoiding vaccinations.

There are simple and effective evidence-based strategies to help manage and reduce needle pain and fear associated with vaccines.





### Limitations

Our rapid review is subject to some limitations. We excluded studies that addressed vaccine hesitancy in non-medically vulnerable groups and, in doing so, may have excluded some studies that included children and youth with medical vulnerability in their findings. We mitigated this risk by working closely with a medical librarian and consulting with medical and patient partner resources. In addition, the evidence on this topic is regularly evolving. For example, there were three studies identified related to COVID-19 vaccination. Since this review was started, additional studies have likely been published about vaccination hesitancy in children and youth with medical vulnerability (see <sup>4,6,9,13</sup>). Finally, with the broad focus on all childhood vaccinations, it is essential to note that we must be careful not to over-generalize the findings and recommendations across different vaccination types and disease conditions. Vaccine hesitancy is not static. A parent or caregiver may have their child vaccinated for a particular vaccination or group of vaccinations; however, they may be hesitant about another vaccine. Nonetheless, the findings can provide some initial insight into what factors impact parents' confidence in children and youth with medical vulnerability.

### Conclusion

Children and youth with medical vulnerability face unique challenges when interacting with the healthcare system. Our rapid review demonstrates a need to reduce barriers and increase equity in accessing childhood vaccinations for children and youth with medical vulnerability and their families. In addition, children and youth with medical vulnerability face regular and ongoing inequalities in society and when accessing healthcare services. As a result, the risk of adverse health outcomes related to vaccine-preventable disease is high. Therefore, decision makers and healthcare professionals must consider the factors that lead to successful vaccine programs and high vaccine uptake.





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Santé des enfants Canada

### Appendix 1: Sample Search Strategy

Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions <1946 to March 22, 2022>

\_\_\_\_\_

One exp Immunization/ (194781)

- 2 Vaccines/ad [Administration & Dosage] (4739)
- 3 (immuni\* or vaccin\*).tw,kf. (622351)
- 4 1 or 2 or 3 (677811)

Search Strategy:

Five adolescent/ or child/ or child, preschool/ or infant/ (3492200)

- 6 Pediatrics/ (57329)
- 7 (adolescen\* or child\* or infant\* or infancy or paediatric\* or pediatric\* or teen\* or youth\*).tw,kf. (2279154)
- 8 5 or 6 or 7 (4205317)
- 9 exp Lung Diseases/ (1094682)
- 10 exp Respiratory Tract Diseases/ (1578544)
- 11 exp Nervous System Diseases/ (2721722)
- 12 exp Heart Diseases/ (1214322)
- 13 Cardiovascular Diseases/ (165174)
- 14 diabetes mellitus/ or exp diabetes mellitus, type 1/ or exp diabetes mellitus, type 2/ (343063)
- 15 exp Infant, Premature, Diseases/ or Infant, Premature/ or exp Premature Birth/ (104510)
- 16 Enteral Nutrition/ (21152)
- 17 exp Immune System Diseases/ (1587309)
- 18 exp Neoplasms/ (3647817)
- 19 ((airway or cardiac or heart or immune system or lung or lungs or neurological or nervous system or pulmonary or respiratory) adj5 (disease\* or disorder\*)).tw,kf. (581482)
- 20 (cancer or diabetes or diabetic or enteral nutrition or feeding tubes or neoplasm\* or prematurity).tw,kf. (2890335)
- 21 (immuno-compromised or immunocompromised or immunodeficien\* or immuno-suppress\* or immunosuppress\* or medical\* vulnerab\* or weak\* immun\*).tw,kf. (348603)
- 22 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 (10433753)
- 23 4 and 8 and 22 (53803)
- 24 exp "patient acceptance of health care"/ or exp treatment refusal/ (178865)





- 25 ((vaccin\* or immuni\*) adj5 (hesitat\* or hesitation\* or hesitanc\* or decision\* or decid\* or accept\* or barrier\* or concern or concerns or facilitat\* or improve or improving or educat\* or increase or increasing or intervention\* or promoting or promotion or refusal or refuse or refusing or declin\* or strategies or strategy or uptake)).ti. (11603)
- 26 24 or 25 (188279)
- 27 23 and 26 (2617)
- 28 limit 27 to english language (2514)
- 29 hospitalization/ or "length of stay"/ or patient admission/ or patient readmission/ (245741)
- 30 Child, Hospitalized/ (7122)
- 31 exp Comorbidity/ (123126)
- 32 (comorbid\* or hospitali\*).tw,kf. (477270)
- 33 (hospital\* adj5 (admit\* or admission\*)).tw,kf. (135486)
- 34 22 or 29 or 30 or 31 or 32 or 33 (10815230)
- 35 4 and 8 and 26 and 34 (2767)
- 36 limit 35 to english language (2652)

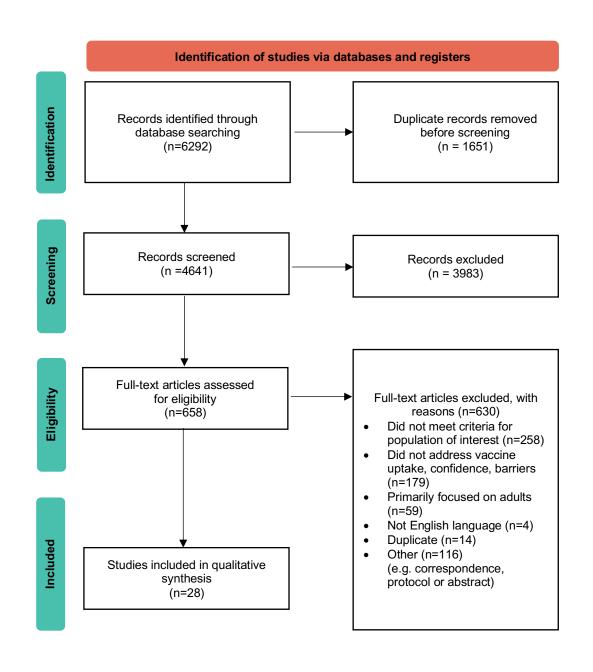
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Santé Healthcare des enfants Canada

### Appendix 2: PRISMA flowchart







### Appendix 3: Needle Pain and Fear Resources



### Needle Pain & Anxiety Management for Vaccination Under 5

### Resources for Children Under 5 Years Old



### SickKids | About Kids Health

- Access here: Pain Learning Hub
- Access here: Comfort Promise Learning Hub



### Les stratégies Tout doux

• Access here: CHU Sainte-Justine



### Psychology Works Fact Sheet: Acute Pain Management in Children

Access here: Canadian Psychological Association



### **Preparing to Immunize**

Access here: <u>Alberta Health Services</u>



### **Pain Narratives and Memory Study**

Access here: <u>Peak Research Lab</u>



### **Toddler Support: Pain Champions Guide**

• Access here: The Meg Foundation



### What to Expect: Vaccines for Children

Access here: Government of Canada



### Immunizing Children with Confidence

Access here: Children's Healthcare Canada



### HealthyChildren.org | Taking Fear and Pain out of Needles

• Access here: <u>HealthyChildren.org</u>



### Indigenous Community Developed Resources

Access here: <u>Lil Reah story</u>
Access here: <u>Lil Louis story</u>
Access here: <u>Children's booklet</u>



### 1-Page Resource: Needles Don't Have to Hurt

• Access here: Parents Canada

### Specific Strategies for Children Under 3 Years Old



### **Immunize Canada Resources**

- Access here: <u>A Clinician's Guide: Pain</u>
   <u>Management During Vaccine Injections:</u>
- Access here: Pain Management During Immunization for Children
- Access here: <u>Reduce Pain of Vaccination in</u> <u>Children under 3 Years: a Guide for Parents</u>



### Needle Pokes: Reducing Pain in Infants up to 18 Months

• Access here: SickKids



### Resources for Babies 0-24 Months

• Access here: The Meg Foundation



### Video Resource: Be Sweet to Babies

Access here: <u>CHEO</u>



### SickKids YouTube Playlist

 Access here: <u>Reducing Pain of Vaccination in</u> <u>Babies</u>



### **Comfort Positioning**

• Access here: Alberta Health Services



### Video Resource: Power of a Parent's Touch

 Access here: <u>Marsha Campbell-Yeo of Dalhousie</u> <u>University and the IWK Health Centre on</u> <u>YouTube</u>

Follow this link for additional resources for Children and Youth Over 5 Years old: <a href="https://tinyurl.com/4hxcpdsp">https://tinyurl.com/4hxcpdsp</a>















### **Needle Pain & Anxiety Management for Vaccinations**

### Resources for Children, Parents, and Families



### Parents Canada 1-Page Resource

Access here: tinyurl.com/ddebsvdy



### **Conversation Canada Articles**

5 simple ways to ease vaccination pain for yourself and your child: tinyurl.com/ccmhzcp2

Needle fears can cause COVID-19 vaccine hesitancy, but these strategies can manage pain and fear: tinyurl.com/23xfpay6



### CARD System: Comfort, Ask, Relax, Distract

Access here: tinyurl.com/2cc82n7j



### It Doesn't Have to Hurt Video

Watch here: tinyurl.com/2esx7k26

For more #ItDoesntHavetoHurt content: www.itdoesnthavetohurt.ca



### Les stratégies Tout doux

Téléchargez ici: tinyurl.com/hr3aczpw



### J'aime pas les piqûres!

Téléchargez ici: tinyurl.com/ra8syhmk



### **Meg Foundation**

Access here: megfoundationforpain.org



### **Government of Canada Resources**

What to expect at your child's vaccination appointment: tinyurl.com/5enbyvnc

À quoi s'attendre lors de la visite de vaccination: tinyurl.com/e49yjzbu



### Mom Hack Video: When Kids are Afraid of Needles

Access here: tinyurl.com/445k97fe



### **Anxiety Canada**

Helping Children with Needle/Vaccine-Related Anxieties: tinyurl.com/uwatncxk

My Anxiety Pain Plan

- Children & teens: tinyurl.com/n6em75kw
- Adults: tinyurl.com/yv8pjbb8



### **Commitment to Comfort**

Access here: tinyurl.com/vancepcb



### Be Sweet to Babies Video Series Available in several languages

Watch here: tinyurl.com/ur2e9vf9

### Resources for Health Professionals and Adults



### **Immunize Canada Resources**

For clinicians: tinyurl.com/279vhnvf

• Children: tinyurl.com/yacva6bd

• Youth: tinyurl.com/362zx5bc

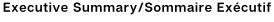
• Adults: tinyurl.com/26reyw2a

La peur des aiguilles et ses répercussions: tinyurl.com/38c59wky



### **Clinical Practice Guidelines**

For needle pain: tinyurl.com/495jnhk3 For needle fear: tinyurl.com/36zksk2b



COVID-19 Vaccine Hesitancy and Needle Fear

Survey: tinyurl.com/3fja3yxj

Enquête sur la réticence à la vaccination contre la

31

COVID-19 et la peur des injections:

tinyurl.com/z6eerzau











### Ressources pour la douleur et l'anxiété liées à la vaccination

### Ressources pour les parents



### **Immunisation Canada**

- Gestion de la douleur lors de la vaccination : <u>tinyurl.com/bc3mu554</u>
- La peur des aiguilles et ses répercussions : tinyurl.com/3rp962fa
- Évanouissement lié aux aiguilles : <u>tinyurl.com/yjhc5bm3</u>

### Guides parentaux:

• Enfants moins de 3 mois : <u>tinyurl.com/2p8jjns3</u>

• Enfants et adolescents : tinyurl.com/2p8mczjw



### **Government of Canada Resources**

 À quoi s'attendre lors de la visite de vaccination : <u>tinyurl.com/e49yjzbu</u>

• Allô les ados ! : tinyurl.com/44aewaf4



### Ministère de la santé et des services sociaux du Québec

Diminuer la douleur et l'anxiété liées à la vaccination chez les enfants : tinyurl.com/yrzhmsbb



### Vidéo #PasBesoinDeFaireMal

Visionnez ici : tinyurl.com/32eujpyj



### Les Explorateurs

Visionnez ici : tinyurl.com/yc6hh8ju



### J'aime pas les piqûres!

Téléchargez ici : tinyurl.com/ra8syhmk



### Les stratégies Tout doux

Téléchargez ici : tinyurl.com/hr3aczpw



### **CHU Sainte-Justine**

Visionnez ici : tinyurl.com/2p8pxddc



### **Petite Douceur**

Visionnez ici : tinyurl.com/2p9x9hk5



### Solutions for Kids in Pain (SKIP)

Quelques faits au sujet de la douleur : <a href="mailto:tinyurl.com/2p9evjep">tinyurl.com/2p9evjep</a>



### Solutions for Kids in Pain (SKIP)

L'Allaitement et ses bénéfices : tinyurl.com/mrxn3zkm

### Ressources pour les soignants



### Immunisation Canada

Système CARD : <u>tinyurl.com/29u55wys</u>
 Pour les cliniciens : <u>tinyurl.com/27eudydm</u>



### Sommaire Exécutif

Enquête sur la réticence à la vaccination contre la COVID-19 et la peur des injections : tinyurl.com/z6eerzau



### The Rounds

Faciliter la vaccination pour les enfants et les parents : <a href="mailto:tinyurl.com/5n88evbj">tinyurl.com/5n88evbj</a>

